

# FATAL

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**M**ICHAEL STOREY was not there to hold his wife Debbie's hand when she died last Tuesday, aged just 40. After a two-day vigil at her hospital bedside, he had gone home, he explains tearfully, 'to make the boys their tea', and she passed away in her mother's arms.

Every word he has uttered about Debbie, however, suggests she would have approved of him putting their sons' needs first. She did it herself, and perhaps paid the ultimate price.

Debbie's is an extraordinary, deeply harrowing and profoundly disturbing story. Her boys — 15-year-old Ben and Sam, 11 — both suffer from Asperger's syndrome, a form of autism, and she spent years fighting to win support for them from a social services system that seemed indifferent to their needs.

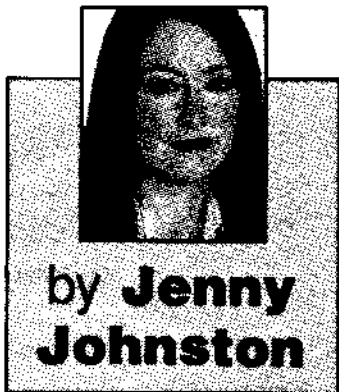
With terrible irony, that very devotion led those same social services to dismiss her effectively as an 'attention-seeker', and even threaten to take her boys away from her for being an unsuitable parent.

Then, say her family, when her body buckled under the strain of her struggle, and she became seriously ill, that tag of being an 'attention-seeker' returned to haunt her, and led to doctors ignoring her symptoms and refusing to believe she was ill.

The truth was that she had cancer — which, as precious time was wasted, spread to the rest of her body. Her funeral is today.

If her family are correct — and their calls for an investigation are being backed by the mental health charity Mencap — Debbie Storey was effectively denied potentially life-saving medical treatment because of a few ill-chosen words on a social services

## A few ill-chosen words may have cost Debbie's life



by **Jenny Johnston**

injustice to a new level. Before she died, Debbie and her husband had spent ten years fighting to get their sons the help they needed for their Asperger's.

The couple, from Rayleigh, Essex, took on everyone — doctors, teachers, education authorities — and enlisted the help of their local MP in a bid to prove that their sons were not just 'slow' or 'odd' or 'disruptive'.

But their persistence had devastating, perhaps even fatal, consequences.

At one point, Essex Social Services cited the boys' unusual behaviour as evidence they were being emotionally abused by Debbie, who herself suffered from Asperger's.

A therapist — who was not an expert in the condition — accused her of being an attention-seeker, and, incredibly, her sons were placed on the 'at-risk' register.

It took a year-long battle with Essex County Council, involving an army of lawyers and medical experts, to have the boys taken off that register. The damage, however, was done.

The attention-seeking 'diagnosis' had followed Debbie through the entire health and social work system. It was even, crucially, on her medical notes.

Last year, Debbie fell ill with a crippling pain in her back, but, mindful of the 'attention-seeking' accusations, was fearful of visiting her GP. When she did, he sent her home with painkillers, and she wept, telling her family that no one believed her.

The pain got worse, and she started vomiting violently. She sought more help. At one stage she was rushed to hospital in an ambulance, but was again sent home with painkillers. On another occasion, she was told her pain was a result of constipation, was given an enema and again sent home.

Another consultant, who would have had access to the same medical notes, wondered at the

to follow Debbie's coffin to the crematorium, quite how much they understand of what has happened is unclear. The nature of Asperger's syndrome means they find it difficult to express emotion, and to communicate what they are feeling.

They have written little notes to place alongside their mother's body, but their father — who says over and over again that he is out of his depth — simply doesn't know how to help them grieve.

'That was Debbie's thing,' says Michael, 42, a former RAF engineer. 'She had Asperger's, too, so she understood.'

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## 'They were like prisoners in a kangaroo court'

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What the Storeys are going through is more than just a devastating family tragedy. There can hardly be a more potent example of what can happen when an all-powerful social services department gets something wrong.

Leading autism expert Lisa Blakemore-Brown, an associate fellow of the British Psychological Society, last night demanded answers.

'Debbie and Michael were treated like prisoners at a medieval kangaroo court. The so-called "experts" failed to recognise the children's autism, and decided the parents were to blame. As a result, the health system wrongly thought Debbie was simply making up her back pain to gain more attention.'

'Now she has died, in agony, and two vulnerable young boys have lost their loving mother, one of the only people in the world who properly understood them.'

Sadly, it is only now becoming evident how determined Debbie was to understand her sons. Her fight to establish what was 'wrong' with them became her life's work. Today, the family home is full of files which document every step of her amazing quest.

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report that became repeated like a mantra throughout the system.

Of course, there are probably rights and wrongs on both sides. And, of course, well-intentioned social workers and medical staff have to make impossible decisions in what are often 'lose-lose' situations.

But today, Debbie's case is being held up by mental health experts as a devastating example of the power — over life and death — wielded by unqualified officials.

The department involved, Essex Social Services, has already come under fire for heavy-handedness. It was exposed in the Mail last month for destroying another loving family by confiscating their children, claiming the parents were 'too slow' intellectually to bring them up properly.

That led to a national outcry and exposed the traumas of a hidden population of people with learning disabilities. But the case of Debbie Storey has taken this

she died, Debbie and her husband had spent ten years fighting to get their sons the help they needed for their Asperger's.

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Another consultant, who would have had access to the same medical notes, wondered if Debbie's Asperger's could have affected her 'perception' of pain.

At no point were her complaints fully investigated, not even when her family pointed out that Debbie's younger brother, Neil, was at that very moment fighting kidney cancer.

In March of this year, the medical profession finally took heed, but only when her family begged Neil's consultant to examine her, too. By then it was too late.

She was found to be suffering from advanced cancer of the kidney, which had spread to her liver and ovaries. Within eight weeks, she was dead, and the boys she'd fought so hard to protect were left without a mother. Today, as Ben and Sam prepare

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Every time she was 'fobbed off', in Michael's words, she took to her writing pad, or to the internet, determined to find answers.

Her pleas for help have outlived her. In one letter, written to an autism expert in desperation, Debbie says: 'They are ripping my family to pieces. There is total ignorance to the needs of a family dealing with autism. This is spiralling out of control and I am going with it.'

Any family touched by autism will understand some of the frustrations she and Michael felt when they first suspected that all was not right with their first-born son.

Perhaps Debbie's fears were rooted in her own experience.

# DEVOTION



Although her autism was not diagnosed until two years ago — after her sons had been diagnosed — she said her own childhood was blighted by her 'odd' behaviour.

A loner at school, and bullied because of her inability to get on with other children, Debbie had left school without a single O-level, despite the fact her parents insisted she was bright. She had been dubbed 'weird' because of a near-compulsive desire for routine.

By the time he was four, Debbie was convinced Ben, displaying the same characteristics, needed help.

'He was obviously really intelligent — at four he'd have complex conversations about Tutan-khamun,' says Michael. 'His speech was incredible, and he just seemed to soak up information.'

'But he didn't like mixing with other children. And he hated physical contact. If you went to give him a cuddle, he would draw away.'



Tireless campaign: Debbie Storey fought for ten years to get suitable treatment for her autistic sons Sam, left, and Ben

**It was straight out of Kafka. When this mother fought to win proper care for her autistic sons, social services branded her an attention-seeker. The slur went on her medical files – and when she got cancer, doctors didn't believe she was ill. Today is her funeral...**

and would fly into a rage if his routine was upset.

His teachers were concerned about his behaviour, which was

## **The experts said it was down to bad parenting**

becoming increasingly violent, but Debbie claimed again and again that her efforts to do something were thwarted.

'She went to the doctor, then the teachers, but got nowhere. She kept asking for someone else to see Ben, but every time the results came back saying there was nothing wrong with him. They said it was bad parenting.

'But he was having a terrible time at school. He was being bullied and was upset. They tested him for dyslexia, dyspraxia, and everything else under the sun.'

Ben was ten when he was finally diagnosed with Asperger's syndrome. By this time, brother Sam, four years his junior, was displaying uncannily familiar signs, being uncommunicative and obsessive.

Michael was, in many ways, relieved when Sam was also diagnosed with Asperger's because this meant the family would be entitled to a whole range of specialist help.

But the fight had only begun. Since 1997, Michael claims, the family have been battling with the local education authority, even though both children were awarded the all-important Statements of Special Educational Needs, which should have guaranteed continuing support.

There have obviously been serious differences of opinion about how best to deal with the boys. At one point, claiming Ben had developed a phobia about school, Debbie and Michael removed him from the education system, and insisted they would teach him at home.

The local education authority insisted he return to school. While the legal tussle went on, the